

This is a statistical abstract of U.S. data on Alzheimer's disease
published by the Alzheimer's Association.



**Every 72 seconds
someone in America
develops Alzheimer's.**

**Alzheimer's Disease Facts and Figures
2007**

alzheimer's  association®

the compassion to care, the leadership to conquer

Table of Contents

Introduction

About This Report	2
Dementia: Definition and Specific Types	2
More About Alzheimer's Disease	3
Symptoms of Alzheimer's Disease.....	3
Causes of Alzheimer's Disease	4
Treatment and Prevention of Alzheimer's Disease	4
History of Alzheimer's Disease	4

Prevalence

Current Prevalence of Alzheimer's	5
Looking to the Future	5
State-by-state Prevalence.....	5

Table 1: Number and Percent Change in People Age 65+ with Alzheimer's Disease Between 2000 and 2010 by State

Mortality

Reporting Alzheimer Deaths	7
Coexisting Medical Conditions.....	7
State-by-state Deaths from Alzheimer's.....	7

Table 2: Percent Change in Selected Leading Causes of Death from 2000 to 2004

Table 3: Percent of Medicare Beneficiaries Age 65+ with Alzheimer's Disease and Other Dementias Who Had Specified Coexisting Medical Conditions, 1999

Table 4: Number of Deaths Due to Alzheimer's Disease and Rate per 100,000 Population by State, 2003

Medicare and Medicaid

Medicare Coverage.....	10
Medicaid Coverage.....	10

Figure 1: Average Medicare Costs for Beneficiaries Age 65+ with Alzheimer's Disease and Other Dementias Compared with Other Beneficiaries, 2000

Table 5: Average Medicare Costs for Beneficiaries Age 65+ with Alzheimer's Disease and Other Dementias Who Had Specified Coexisting Medical Conditions, 2000

Costs of Alzheimer's Disease

Costs to Federal and State Government and Business ..	13
Costs to Individuals and Their Families	13

Table 6: Total Business Costs for Alzheimer's Disease, 1998 and 2002

Figure 2: Average Medicare Costs for Hospital, Nursing Home and Home Health Care for Beneficiaries Age 65+ with Alzheimer's Disease and Other Dementias Compared with Other Beneficiaries, 2000

Use of Services

Care Settings	15
Long-term Care	15
End-of-life Care	15

Table 7: Cognitive Impairment in Nursing Home Residents by State, 2005

Special Report: Caregiving

Caregivers of People with Alzheimer's Disease and Other Dementias	17
The Challenges of Caregiving.....	17
Stress Associated with Caregiving	17
The Economic Value of Caregiving.....	18

Table 8: Number of Alzheimer and Dementia Caregivers, Hours of Unpaid Care and Economic Value of Care, by State, 2005

Table 9: Helping with Specific Daily Activities: Alzheimer Caregivers Compared With Other Caregivers

Appendix

Methodology.....	21
Sources	23

Introduction

About This Report

Alzheimer's Disease Facts and Figures is a comprehensive statistical abstract of U.S. data on Alzheimer's disease, the most common type of dementia. To provide background and context for interpreting the data, the Introduction defines dementia, summarizes current knowledge about Alzheimer's disease, and briefly explains other specific types of dementia.

Statistical benchmarks documented in *Alzheimer's Disease Facts and Figures* include:

- Overall number of Americans with Alzheimer's disease, and estimates by specific age groups and for each state;
- Projections of the future growth of Alzheimer's;
- Number of deaths due to the disease;
- Costs to federal and state government, businesses and individuals and their families;
- Use of services in the home, hospitals, nursing homes and other care settings;
- Impact on Medicare and Medicaid;
- Number of family caregivers; hours of care provided; the economic value of unpaid care for the United States and each state; and the personal impact of caregiving on caregivers.

The techniques used to derive current prevalence and incidence figures and projections of future prevalence and incidence are explained in the Methodology section in the Appendix.

Many research studies and surveys included here do not differentiate among Alzheimer's disease and other dementias, because these disorders as a group tend to have similar symptoms, impact and health outcomes. As a result, this report frequently cites statistics that apply broadly to individuals with all types of dementia. In some cases, the reference is to "Alzheimer's disease and other dementias."

The following sections of the Introduction discuss the formal definition of dementia, details about Alzheimer's disease, and the relationship between Alzheimer's and other types of dementia.

Dementia: Definition and Specific Types

"Dementia" is the general term for a group of disorders that cause irreversible cognitive decline as a result of various biological mechanisms that damage brain cells. To be classified as a type of dementia, a disorder must meet the following two criteria:

1. It must cause decline in at least two of the following four essential cognitive functions:

- (i) memory;
 - (ii) ability to generate coherent speech or understand spoken or written language;
 - (iii) capacity to plan, make sound judgments and carry out complex tasks; and
 - (iv) ability to process and interpret visual information.
2. The decline must be severe enough to interfere with day-to-day life.

Different types of dementia are historically associated with distinct symptom patterns and distinguishing microscopic brain abnormalities. Increasing evidence from long-term epidemiological observation and autopsy studies suggests these distinctions are somewhat artificial. Symptoms and pathologies frequently overlap, and can be further complicated by coexisting health conditions.

Current classification of specific types of dementia:

Alzheimer's disease is the most common dementia, accounting for 50 to 70 percent of cases. Its "classic" symptom pattern begins with memory loss for recent events. Its two hallmark abnormalities are (1) plaques, deposits of a protein fragment called beta-amyloid, and (2) tangles, twisted strands of another protein called tau. Alzheimer's disease is discussed in more detail in the following sections.

Vascular dementia (also called multi-infarct dementia, post-stroke dementia or vascular cognitive impairment) is widely considered the second most common type after Alzheimer's disease. Impairment is caused by reduced blood flow to parts of the brain, often due to a series of tiny strokes blocking small arteries. Symptoms often overlap with those of Alzheimer's disease, although memory may or may not be as seriously affected as in Alzheimer's, depending on whether the blockage occurs in the brain's memory regions.

Mixed dementia is characterized by the presence of hallmark abnormalities of both Alzheimer's disease and vascular dementia. Many experts believe mixed dementia is also very common.

Parkinson's disease primarily affects movement, resulting in tremors, stiffness, difficulty walking, and impaired speech. A significant percentage of individuals with Parkinson's disease also develop dementia in later stages of the disease. The hallmark abnormality in Parkinson's disease is Lewy bodies, deposits of a protein called alpha-synuclein, in a specific brain region critical for control of movement. Lewy bodies also occur in different brain regions in other types of dementia, including dementia with Lewy bodies and some cases of Alzheimer's disease.

Dementia with Lewy bodies can cause a pattern of decline similar to Alzheimer's disease, involving problems with memory, confusion and poor judgment. Alertness and severity of cognitive symptoms may fluctuate significantly from day to day. Individuals usually experience visual hallucinations as well as muscle rigidity and tremors. Lewy bodies are deposits of a protein called alpha-synuclein.

Frontotemporal dementia is a disorder in which cellular damage tends to concentrate in the front and side regions of the brain. There are two typical symptom patterns involving (1) changes in personality and behavior, or (2) significant difficulty with language. There is no distinguishing microscopic abnormality currently linked to all cases of frontotemporal dementia. One type, called Pick's disease, is characterized by "Pick's bodies."

Creutzfeldt-Jakob disease is a rapidly fatal disorder that impairs memory and coordination and causes behavior changes. "Variant Creutzfeldt-Jakob disease" was recently identified as the human disorder believed to be caused by consumption of products from cattle affected by "mad cow disease." These disorders are caused by a chain-reaction misfolding of prion protein throughout the brain.

Normal pressure hydrocephalus is caused by a buildup of fluid in the brain. The cause of most cases is unknown. Symptoms include difficulty walking, memory loss and inability to control urine. The disorder can sometimes be corrected with surgical installation of a shunt to drain the excess fluid.

Mild cognitive impairment (MCI) is a condition in which a person has a problem with memory, language or another essential cognitive function serious enough to be noticeable to others and to show up on tests, but not severe enough to interfere with daily life. Some, but not all, people with MCI develop dementia over time, especially when their primary area of difficulty involves memory.

More About Alzheimer's Disease

In Alzheimer's disease, as in other types of dementia, increasing numbers of nerve cells deteriorate and die. A healthy adult brain has 100 billion nerve cells, or neurons, with long branching extensions connected at 100 trillion points. At these connections, called synapses, information flows in tiny chemical pulses released by one neuron and taken up by the receiving cell. Different strengths and patterns of signals move constantly

through the brain's circuits, creating the cellular basis of memories, thoughts and skills.

In Alzheimer's disease, information transfer at the synapses begins to fail, the number of synapses declines and, eventually, cells die. In a brain with advanced Alzheimer's there is dramatic shrinkage from cell loss and widespread debris from dead and dying neurons.

Scientists do not yet know what causes the catastrophic brain damage associated with Alzheimer's disease. According to a leading theory, called the "amyloid hypothesis," the prime suspect is a tiny protein fragment called beta-amyloid. Trouble begins when yet-to-be-identified factors trigger overproduction of beta-amyloid or reduce the brain's ability to dispose of it. The excess jams signaling at the synapses, blocking information flow and leading to a "cascade" of damaging events ending in cell death.

Beta-amyloid fragments gradually accumulate into the microscopic "plaques" considered to be one pathological hallmark of Alzheimer's. The other hallmark is "tangles," formed when a different protein called tau twists into strands inside dead and dying neurons. Other abnormalities seen in Alzheimer brain tissue include inflammation and oxidative stress, damage from highly reactive oxygen-containing products of cellular metabolism.

Symptoms of Alzheimer's Disease

Alzheimer's disease can affect different people in different ways, but the most common symptom pattern begins with gradually worsening difficulty remembering new information. This is because disruption of brain cells usually begins in regions involved in forming new memories. As damage spreads, individuals also experience confusion, disorganized thinking, impaired judgment, trouble expressing themselves and disorientation. In advanced Alzheimer's, people need help with bathing, dressing, using the bathroom, eating and other day-to-day activities. Those in the final stages of the disease lose their ability to communicate, fail to recognize loved ones and become bed-bound. Alzheimer's disease is ultimately fatal.

Although most families prefer to keep the person with Alzheimer's at home as long as possible, nearly everyone with the disease eventually needs more assistance than families and friends can provide, and moves into a long-term care setting.

Causes of Alzheimer's Disease

In the vast majority of cases, the cause of Alzheimer's disease remains unknown. Most experts agree that Alzheimer's, like other common, chronic conditions, likely develops as a result of multiple factors rather than a single cause. The greatest risk factor by far is advancing age. Most Americans with Alzheimer's disease are age 65 or older.

A tiny percentage of Alzheimer's disease is caused by rare genetic variations found in a few hundred families worldwide. In these inherited forms of Alzheimer's, the disease tends to develop before age 65, sometimes in individuals as young as 30.

Individuals younger than age 65 can also develop the more common form of Alzheimer's that usually appears later in life.

When Alzheimer's or another type of dementia is first recognized in a person under age 65, these conditions are referred to as "early-onset Alzheimer's" or "early-onset dementia."

Treatment and Prevention of Alzheimer's Disease

There is not yet any treatment that can delay or stop the deterioration of brain cells in Alzheimer's disease. The U.S. Food and Drug Administration (FDA) has so far approved five drugs that temporarily slow worsening of symptoms for about 6 to 12 months, on average, for about half of the individuals who take them. Based on deepening insight into the underlying biology of Alzheimer's and emerging conceptual frameworks for understanding the disease, researchers have identified a number of new treatment strategies that may have the potential to change its course. A number of experimental therapies based on the amyloid hypothesis and other targets have reached various stages of clinical testing in human volunteers.

Despite the current lack of disease-modifying therapies, studies have consistently shown that active medical management of Alzheimer's and other dementias can significantly improve quality of life through all stages of the disease for diagnosed individuals and their caregivers. Active management includes appropriate use of available treatment options, effective integration of coexisting conditions into the treatment plan and utilization of programs and support services.

Many scientists consider the emerging field of prevention one of the most exciting recent developments in the dementia research arena. A growing body of evidence suggests that the health of the brain – one of the body's most highly vascular organs – is closely linked to the overall health of the heart and blood vessels. Beginning in young adulthood, management of such cardiovascular risk factors as cholesterol and blood sugar levels, blood pressure and weight may help avoid or delay cognitive decline. Additional evidence points to a significant role for regular physical exercise in maintaining lifelong cognitive health. Still other evidence suggests that a low-fat diet rich in fruits and vegetables may support brain health, as may a robust social network and a lifetime of intellectual curiosity and mental stimulation.

History of Alzheimer's Disease

The year 2006 marked the 100th anniversary of a small medical meeting in Tübingen, Germany, where physician Alois Alzheimer presented the haunting case of Auguste D. Alzheimer first saw Auguste in 1901 when she was 51. She was plagued by symptoms that did not fit any known diagnosis: rapidly failing memory, confusion, disorientation, trouble expressing her thoughts and unfounded suspicions about her family and the hospital staff.

Auguste died after four years of steady decline that left her bedridden and mute, and Alzheimer performed an autopsy. In her brain, he found dramatic shrinkage, widespread dead and dying cells and two kinds of microscopic deposits he'd never seen before. "All in all," he wrote in his presentation abstract, "we are faced obviously with a peculiar disease process."

This mysterious, harrowing disorder soon entered the medical literature as "Alzheimer's disease." The unusual brain deposits gained recognition as its pathological hallmarks, and became known as "plaques" and "tangles."

In 1915, Alois Alzheimer himself died at age 51, never suspecting that his encounter with Auguste D. would one day touch the lives of millions and drive a massive international research effort.

Prevalence

The Current Prevalence of Alzheimer’s

An estimated 5.1 million Americans have Alzheimer’s disease in 2007. This number includes 4.9 million people age 65 and older. It also includes at least 200,000 individuals younger than 65 with early-onset Alzheimer’s. The Alzheimer’s Association estimates there are approximately 500,000 Americans younger than 65 with Alzheimer’s or another dementia. At a conservative estimate, at least 40 to 50 percent of them are likely to have Alzheimer’s disease.¹

By age group, the proportion and number of the 4.9 million Americans age 65 and over with Alzheimer’s disease breaks down as follows:

- Age 65-74: 2 percent 300,000 people
 - Age 75-84: 19 percent 2,400,000 people
 - Age 85+: 42 percent 2,200,000 people
- 13 percent, or one in eight, persons age 65 and over have Alzheimer’s disease.
 - Nearly half of persons over age 85 have Alzheimer’s disease.
 - Every 72 seconds, someone in America develops Alzheimer’s disease; by mid-century, someone will develop Alzheimer’s every 33 seconds.

These figures reflect the total number of Americans estimated to have Alzheimer’s, whether or not they have ever been diagnosed with the disease. Many people with Alzheimer’s disease and other dementias have not been diagnosed, and even if they have, their diagnosis may not be noted in their medical record. In one recent study of patients age 65 and older in seven urban, racially diverse primary care practices in Indianapolis, less than one fifth of those with Alzheimer’s or another dementia had a diagnosis of the condition in their medical record.

Looking to the Future

The number of Americans surviving into their 80s and 90s is expected to grow because of national demographics as well as advances in medicine, medical technology and other social and environmental improvements. Since the incidence and prevalence of Alzheimer’s disease increase with advancing age, the number of persons with the disease is expected to grow as a proportion of this larger older population.

- In 2000, there were an estimated 411,000 new cases of Alzheimer’s disease. That number is expected to increase to 454,000 new cases a year by 2010, 615,000 new cases a year by 2030 and 959,000 new cases a year by 2050.
- The number of people age 65 and over with Alzheimer’s disease is estimated to be 7.7 million in 2030, a greater than 50 percent increase over the number currently affected.
- According to the U.S. Census Bureau, as of July 1, 2005, there were an estimated 78.2 million American baby boomers (those born between 1946 and 1964). In 2006, baby boomers began turning 60 at a rate of about 330 every hour. In 2011, baby boomers begin turning 65, reaching the age of greatest risk for Alzheimer’s disease.
- By 2050, the number of individuals age 65 and over with Alzheimer’s could range from 11 million to 16 million unless science finds a way to prevent or effectively treat the disease. By that date, more than 60 percent of people with Alzheimer’s disease will be age 85+.

State-by-state Prevalence

The proportion of older adults in the age groups 65-74, 75-84 and 85+ varies by state. Because the incidence and prevalence of Alzheimer’s disease increase with age, states with a higher proportion of people in the older age groups are also likely to have a higher proportion of people with the disease.

Table 1 shows the estimated number of people age 65 and over with Alzheimer’s disease for each state in 2000 and 2010, and the percent change expected over this decade. The figures are based on state estimates for 2000, population projections from the U.S. Census Bureau and state-specific adjustments for gender, race, education and mortality.

¹ For explanation of the methodology used to arrive at the prevalence and incidence figures and projections of future prevalence and incidence, see Methodology beginning on page 21.

TABLE 1

**Number and Percent Change in People
Age 65+ With Alzheimer's Disease
Between 2000 and 2010 by State**

Source: Hebert LE, Scherr PA, Bienias JL, Bennett DA, and Evans DA. "State-specific Projections Through 2025 of Alzheimer Disease Prevalence." *Neurology* 2004. (For further details, see Sources in the Appendix.)

	2000	2010	% change 2000 - 2010
Alabama	84,000	91,000	8
Alaska	3,400	5,000	47
Arizona	78,000	97,000	24
Arkansas	56,000	60,000	7
California	440,000	480,000	9
Colorado	49,000	72,000	47
Connecticut	68,000	70,000	3
Delaware	12,000	14,000	17
District of Columbia	10,000	9,100	-9
Florida	360,000	450,000	25
Georgia	110,000	120,000	9
Hawaii	23,000	27,000	17
Idaho	19,000	26,000	37
Illinois	210,000	210,000	0
Indiana	100,000	120,000	20
Iowa	65,000	69,000	6
Kansas	50,000	53,000	6
Kentucky	74,000	80,000	8
Louisiana	73,000	83,000	14
Maine	25,000	25,000	0
Maryland	78,000	86,000	10
Massachusetts	120,000	120,000	0
Michigan	170,000	180,000	6
Minnesota	88,000	94,000	7
Mississippi	51,000	53,000	4
Missouri	110,000	110,000	0
Montana	16,000	21,000	31
Nebraska	33,000	37,000	12
Nevada	21,000	29,000	38
New Hampshire	19,000	22,000	16
New Jersey	150,000	150,000	0
New Mexico	27,000	31,000	15
New York	330,000	320,000	-3
North Carolina	130,000	170,000	31
North Dakota	16,000	18,000	13
Ohio	200,000	230,000	15
Oklahoma	62,000	74,000	19
Oregon	57,000	76,000	33
Pennsylvania	280,000	280,000	0
Rhode Island	24,000	24,000	0
South Carolina	67,000	80,000	19
South Dakota	17,000	19,000	12
Tennessee	100,000	120,000	20
Texas	270,000	340,000	26
Utah	22,000	32,000	45
Vermont	10,000	11,000	10
Virginia	100,000	130,000	30
Washington	83,000	110,000	33
West Virginia	40,000	44,000	10
Wisconsin	100,000	110,000	10
Wyoming	7,000	10,000	43

Mortality

Reporting Alzheimer Deaths

The U.S. Standard Certificate of Death mandated by the Department of Health and Human Services provides for qualified medical personnel or coroners to record a single “underlying cause of death.” This is commonly defined as the disease or injury initiating the train of events leading directly to death. Each certificate may list up to 20 additional diseases and conditions as “contributing causes” of death.

According to the Centers for Disease Control and Prevention (CDC), Alzheimer’s disease was listed as the “underlying cause of death” for 65,829 Americans in 2004. It was the seventh leading cause of death for people of all ages and the fifth leading cause of death in people age 65 and older.

The total number of deaths attributed to Alzheimer’s disease has increased over the last 15 years. In 1991, only 14,112 death certificates recorded Alzheimer’s as the underlying cause. From 2000 to 2004, deaths from Alzheimer’s disease increased by 32.8 percent, while the number one cause of death, heart disease, decreased by 8.0 percent. (See Table 2 showing the number of deaths and percent change in number of deaths from selected diseases between 2000 and 2004).

Even though deaths attributed to Alzheimer’s are increasing, the number may fail to reflect the disease’s real public health impact. Numerous studies have suggested that death certificates substantially underreport Alzheimer’s disease as a cause of death for people living in the community. Because most individuals with Alzheimer’s are age 65 and older, they also tend to have other serious coexisting medical conditions associated with aging, such as heart disease or stroke. Physicians may tend to attribute death primarily to one of these other conditions even when Alzheimer’s disease is present. In the large percentage of cases where the medical record fails to reflect an Alzheimer diagnosis, the certifying physician may not be aware the individual had Alzheimer’s.

In cases where Alzheimer’s is not listed as the underlying cause of death, it may not even be listed as a contributing factor. Nevertheless, people with Alzheimer’s disease in all age groups generally have decreased survival compared with survival in the general U.S. population. One 2004 study by Larson and colleagues noted that people newly diagnosed with Alzheimer’s survived about half as long as those of similar age who did not

have the disease. In this study, average survival time was four to six years after diagnosis, but survival can be as long as 20 years from first symptoms.

The mechanisms by which dementia leads to death may create ambiguity about the underlying cause. Severe dementia frequently causes such complications as immobility, swallowing disorders or malnutrition. These complications can significantly increase the risk of developing pneumonia, which has been found in several studies to be the most common identified cause of death among elderly persons with Alzheimer’s disease and other dementias. One researcher described the situation as a “blurred distinction between death *with* dementia and death *from* dementia.”

Coexisting Medical Conditions

Other serious health conditions can develop or coexist in people with Alzheimer’s disease and other dementias, leading to major medical consequences and contributing to the higher likelihood of death for those with dementia. For example, 60 percent of Medicare beneficiaries age 65+ with Alzheimer’s and other dementias also suffer from hypertension, and 30 percent have coronary artery disease. (See Table 3 showing the proportion of Medicare beneficiaries with Alzheimer’s disease and other dementias who also have various coexisting medical conditions.)

As a result of these coexisting conditions, people with Alzheimer’s and other dementias often face frequent hospitalizations for treatment of one or more of the conditions. These conditions also increase likelihood of entering a nursing home and dying there.

- The most common causes of hospitalization for nursing home residents with Alzheimer’s and other dementias are pneumonia and other infections.
- Cardiopulmonary resuscitation is three times less likely to be successful in a person with dementia.

State-by-state Deaths from Alzheimer’s

The highest death rate attributed to Alzheimer’s disease in 2003² was in North Dakota, where the rate was 53 per 100,000 (336 deaths); the lowest rate was 8.6 per 100,000 in Alaska, or 56 deaths. (See Table 4.) Differences across states in death rates attributed to Alzheimer’s disease reflect state demographics, differences in reporting practices and other factors.

² Although national figures from the Centers for Disease Control and Prevention are available for 2004, the most recent state-by-state figures are for 2003.

TABLE 2**Percent Change in Selected Leading Causes of Death from 2000 to 2004**

Cause	2000	2004	% change
Heart disease	710,760	654,092	- 8.0
Breast cancer	41,200	40,110	- 2.6
Prostate cancer	31,900	29,900	- 6.3
Stroke	167,661	150,147	-10.4
Alzheimer's disease	49,558	65,829	+32.8

Source: Centers for Disease Control and Prevention, National Vital Statistics Reports, and Reports of the American Cancer Society. (For further details, see Sources in the Appendix.)

TABLE 3**Percent of Medicare Beneficiaries Age 65+ with Alzheimer's Disease and Other Dementias Who Had Specified Coexisting Medical Conditions (1999)**

Co-Existing Condition	% with the Condition
Hypertension	60
Coronary artery disease	30
Congestive heart failure	28
Osteoarthritis	26
Diabetes	21
Chronic obstructive pulmonary disease	17
Peripheral vascular disease	19
Stroke – late effects	10
Thyroid disease	16

Source: Bynum JPW, Rabins PV, Weller W, et al. *Journal of the American Geriatrics Society* 2004. (For further details, see Sources in the Appendix.)

TABLE 4

Number of Deaths Due to Alzheimer's Disease and Rate per 100,000 Population by State, 2003

Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics Report 2006: 54 (13).

Number of deaths and the rate per 100,000 population are reported by the Centers for Disease Control and Prevention through the National Vital Statistics Reports. The most recent report by state is from Vol. 54, No. 13, published April 19, 2006.

	Number of Deaths	Rate per 100,000
Alabama	1,268	28.2
Alaska	56	8.6
Arizona	1,703	30.5
Arkansas	552	20.3
California	6,585	18.6
Colorado	899	19.8
Connecticut	612	17.6
Delaware	147	18.0
District of Columbia	95	16.8
Florida	4,316	25.4
Georgia	1,630	18.8
Hawaii	161	12.8
Idaho	355	26.0
Illinois	2,626	20.8
Indiana	1,515	24.5
Iowa	887	30.1
Kansas	781	28.7
Kentucky	1,072	26.0
Louisiana	1,184	26.3
Maine	467	35.8
Maryland	865	15.7
Massachusetts	1,609	25.0
Michigan	2,133	21.2
Minnesota	1,243	24.6
Mississippi	583	20.2
Missouri	1,293	22.7
Montana	235	25.6
Nebraska	461	26.5
Nevada	309	13.8
New Hampshire	286	22.2
New Jersey	1,636	18.9
New Mexico	360	19.2
New York	1,866	9.7
North Carolina	2,145	25.5
North Dakota	336	53.0
Ohio	2,902	25.4
Oklahoma	794	22.6
Oregon	1,157	32.5
Pennsylvania	2,952	23.9
Rhode Island	303	28.2
South Carolina	1,051	25.3
South Dakota	174	22.8
Tennessee	1,466	25.1
Texas	4,015	18.2
Utah	332	14.1
Vermont	171	27.6
Virginia	1,466	19.8
Washington	2,380	38.8
West Virginia	470	21.6
Wisconsin	1,411	25.8
Wyoming	142	28.3
United States	63,457	21.8

Medicare and Medicaid

Medicare and Medicaid are health services programs that provide important resources for older adults.

- Medicare is a medical insurance program available to all Americans age 65 and over, and to a limited number of younger individuals who meet the rigorous requirements for Social Security Disability Insurance (SSDI). Participants pay premiums that entitle them to coverage for physician services, hospital care, home health care and prescription drugs. Medicare does not cover long-term care in a nursing home. It will cover short stays in “skilled nursing facilities” when the need for admission immediately follows hospitalization for an acute illness, such as a heart attack or broken hip. The premiums collected do not cover the full cost of services to beneficiaries, and the program is tax-supported.
- Medicaid is a publicly funded health services program for low-income Americans. It is jointly funded by the federal government and states, according to a complex formula. In addition to basic health services, Medicaid covers nursing home care and various home- and community-based long-term care services for individuals who meet program requirements for level of care, income and assets.

Medicare Coverage

Almost all Americans age 65 and older, including those with Alzheimer’s disease and other dementias, participate in Medicare.

Medicare beneficiaries with Alzheimer’s disease and other dementias use significantly more services and have significantly higher costs than other beneficiaries. These disparities are reflected in the figures below representing comparisons with other Medicare beneficiaries in 2000:

- As shown in Figure 1, Medicare spends nearly three times as much, on average, for people with Alzheimer’s and other dementias as for a beneficiary without dementia (\$13,207 versus \$4,454 per beneficiary).
- Beneficiaries with Alzheimer’s and other dementias had 3.4 times more hospital stays than the average for other beneficiaries.
- Costs for hospital care were 3.2 times higher than the average for other Medicare beneficiaries (\$7,704 versus \$2,204).
- Beneficiaries with Alzheimer’s and other dementias visited a physician 1.3 times more often than other Medicare beneficiaries.

People with Alzheimer’s and other dementias often suffer from one or more other chronic illnesses or conditions. Among beneficiaries with such costly conditions as coronary heart disease, diabetes or chronic pulmonary disease, Medicare costs

are more than double when dementia is present. Dementia complicates the care for these conditions, and thereby drives up the cost.

- Ninety-five percent of Medicare beneficiaries age 65 and over with Alzheimer’s and other dementias have at least one other chronic condition, including congestive heart failure, coronary heart disease, diabetes and/or chronic obstructive pulmonary disease.
- Average Medicare costs for a beneficiary with heart disease and Alzheimer’s or other dementia were \$21,538 in 2000, compared with \$11,078 for a beneficiary with heart disease and no Alzheimer’s or other dementia. Likewise, average Medicare costs for a beneficiary with diabetes and Alzheimer’s or another dementia were \$19,994, compared to \$8,011 for a beneficiary with diabetes but no dementia.
- Average hospital costs for a beneficiary with heart disease and Alzheimer’s or other dementias were \$12,273 in 2000, compared with \$6,559 for a beneficiary with heart disease and no dementia. Likewise, average hospital costs for a beneficiary with diabetes and Alzheimer’s or another dementia were \$10,943, compared with \$4,207 for a beneficiary with diabetes but no dementia.

Table 5 compares Medicare costs for people with and without dementia and heart disease, diabetes, congestive heart failure and chronic obstructive pulmonary disease, broken out by hospital, skilled nursing facility and home health care.

Medicaid Coverage

Twenty-nine percent of Medicare beneficiaries age 65+ with Alzheimer’s disease or other dementias are also Medicaid beneficiaries. Of that total, about half were nursing home residents, and half were living in the community.

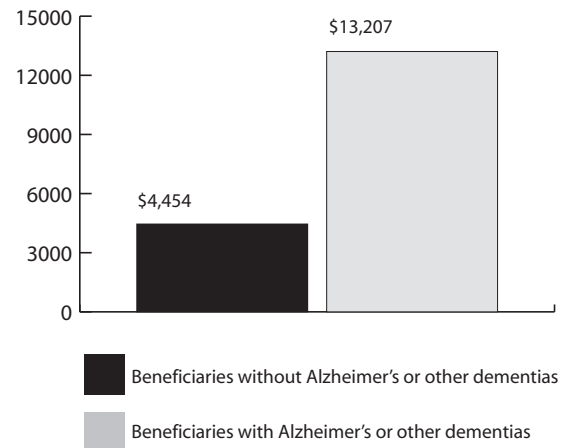
- Among nursing home residents with Alzheimer’s disease and other dementias, 51 percent relied on Medicaid to help pay for their nursing home care in 2000.
- Detailed income and asset data are not available for those with Alzheimer’s or other dementias, but the median income for all women age 65 or older in 2004 was \$12,080; for men, it was \$21,102. The median income for households headed by an older person was \$24,509. (The median represents the middle figure in a range; half of the values fall below the median, and the other half exceed it.) Even for older adults whose incomes fall comfortably above the median, nursing home care, which cost an average of \$75,190 in 2006, can quickly exhaust their resources.
- Two-thirds of elderly people living in the community, and 84

percent of those at high risk of needing nursing home care, have assets that would pay for less than a year in a nursing home. Fifty-seven percent of the elderly in the community and 75 percent of those at high risk of needing nursing home care do not have enough assets to cover even a month in a nursing home.

- Nursing home residents who qualify for Medicaid must spend all of their Social Security check and any other monthly income, except for a very small personal needs allowance, to pay the nursing home. Medicaid only makes up the difference if the resident cannot pay the full cost of care.
- When baby boomers with severe disabilities or diseases like Alzheimer's disease begin to reach the median age for admission to a nursing home in 2025, Medicaid long-term care spending will skyrocket. Medicaid costs for nursing home care alone will climb from \$21 billion in 2005 to \$38 billion in 2025.
- Among older people with Alzheimer's disease and other dementias who were living in the community, 18 percent relied on Medicaid to help pay for their care in 2000. Depending on which home- and community-based services are covered by Medicaid in their state, these people could receive personal care (for example, assistance with bathing and dressing), homemaker, adult day care and respite services.

FIGURE 1

Average Medicare Costs for Beneficiaries Age 65+ with Alzheimer's Disease and Other Dementias Compared with Costs for Other Beneficiaries, 2000



Source: *Alzheimer's Association. Alzheimer's Disease and Chronic Health Conditions: The Real Challenge for 21st Century Medicare*, 2003. (For further details, see Sources in the Appendix.)

TABLE 5

Average Medicare Costs for Beneficiaries Age 65+ with Alzheimer's Disease and Other Dementias Who Had Specified Coexisting Medical Conditions, 2000

Medicare Beneficiaries Age 65+	Average Medicare costs per person	Average hospital costs per person	Average SNF costs per person	Average home health costs per person
All beneficiaries	\$5,329	\$2,640	\$383	\$238
All beneficiaries with no AD/D	4,454	2,204	210	190
All with AD/D	13,207	7,074	2,144	728
With CHD				
CHD and no AD/D	11,078	6,559	526	391
CHD + AD/D	21,538	12,273	3,329	1,013
With Diabetes				
Diabetes and no AD/D	8,011	4,207	420	455
Diabetes+AD/D	19,994	10,943	3,021	1,265
With CHF				
CHF and no AD/D	15,441	9,441	1,016	765
CHF + AD/D	22,939	13,178	3,658	1,222
With COPD				
COPD and no AD/D	12,450	7,580	744	463
COPD + AD/D	23,693	13,980	3,643	992

SNF = Medicare-covered skilled nursing facility

AD/D = Alzheimer's disease and other dementias

CHD = Coronary heart disease

CHF = Congestive heart failure

COPD = Chronic obstructive pulmonary disease, including emphysema

Source: Alzheimer's Association. *Alzheimer's Disease and Chronic Health Conditions: The Real Challenge for 21st Century Medicare* 2003.

(For further details, see Sources in the Appendix.)

Costs of Alzheimer's Disease

Alzheimer's disease and other dementias not only cause enormous suffering to the persons affected by the conditions and emotional and financial burden to their caregivers, they also rob the nation of vast resources. The drain on federal and state budgets and losses to American business rise each year as the number of persons with Alzheimer's and other dementias grows with the aging of the population.

Costs to Federal and State Government and Business

Direct and indirect costs of Alzheimer's and other dementias, including Medicare and Medicaid costs and the indirect cost to business of employees who are caregivers of persons with Alzheimer's, amount to more than \$148 billion annually.

- In 2005, Medicare spent \$91 billion on beneficiaries with Alzheimer's and other dementias, projected to increase to \$160 billion by 2010 and \$189 billion by 2015.
- State and federal Medicaid spending for nursing home care for people with Alzheimer's and other dementias was estimated at \$21 billion in 2005. It is projected to increase to \$24 billion in 2010 and \$27 billion in 2015.
- Costs to business for employees who are caregivers of people with Alzheimer's and other dementias amount to \$36.5 billion. These costs result from lost productivity, missed work and costs to replace workers who leave their jobs to meet the demands of caregiving.

(See Table 6 for total business costs for Alzheimer's disease in 1998 and 2002.)

Costs to Individuals and Their Families

Although Medicare and Medicaid cover some health care costs for older beneficiaries, many expenses of caring for a person with Alzheimer's disease or another dementia must be paid for by the person or family. According to an AARP analysis, Medicare beneficiaries age 65 and older spent an average of \$3,455 (22 percent) of their income on health care in 2003. About 45 percent of those expenses were for Medicare Part B premiums, private Medicare plans (such as HMOs), and private supplemental insurance. Medicare beneficiaries age 65+ paid 37 percent of the cost of nursing home care out of pocket in 2002, the most recent year for which expenditure figures are available by type of medical service.

Out-of-pocket expenditures for health and long-term care are higher, on average, for older people with Alzheimer's and other dementias than for other older people. One analysis based on a large, nationally representative sample from the Health and Retirement Study found that in 1995, average out-of-pocket expenditures for hospitalization, nursing home care stays, outpatient treatment, home care and prescription medications were \$1,350 for people with no dementia and \$2,150 for people with mild or moderate dementia, an increase of \$800³. For people with severe dementia, average out-of-pocket expenditures were \$3,010 in 1995, an increase of \$1,660 over the average for people with no dementia.

The study found that the \$1,660 increase in out-of-pocket expenses for people with severe dementia was greater than the increase in expenditures for people with any of the other conditions included in the analysis. The increases for those other conditions were: heart disease, \$670; stroke, \$820; diabetes, \$760; hypertension, \$630; cancer, \$670; lung disease, \$460; psychiatric problems, \$630; and arthritis, \$270. The \$800 increase in out-of-pocket expenditures for people with mild-to-moderate dementia was greater than the increase for people with any of those other conditions except stroke.

No matter what the funding source, costs are high for care at home or in an adult day center, assisted living facility or nursing home.

- The average hourly rate for home health aides in 2006 was \$19, or \$152 for an eight-hour day. For homemaker or companion services, costs ran about \$17 an hour.
- Adult day services cost an average of \$56 per day, but can range from \$25 to more than \$100 per day, depending on the services offered and geographic region.
- The average monthly cost for a private, one-bedroom unit in an assisted living facility was \$2,968, or \$35,616 a year in 2006. (Assisted living facilities that provide specialized dementia care often charge additional fees ranging from \$750 to \$2,200 monthly for that care.)
- The average daily cost for a private room in a nursing home was \$206 in 2006, or \$75,190 a year.

(See Figure 2 for average Medicare costs for beneficiaries with Alzheimer's compared with other Medicare beneficiaries by type of service.)

³ These figures are in 1995 dollars, without adjustment for inflation. The figures were adjusted for many other factors, including a person's other medical conditions, age, race, gender, marital status, living situation and insurance coverage.

TABLE 6

Total Business Costs for Alzheimer's Disease, 1998 and 2002

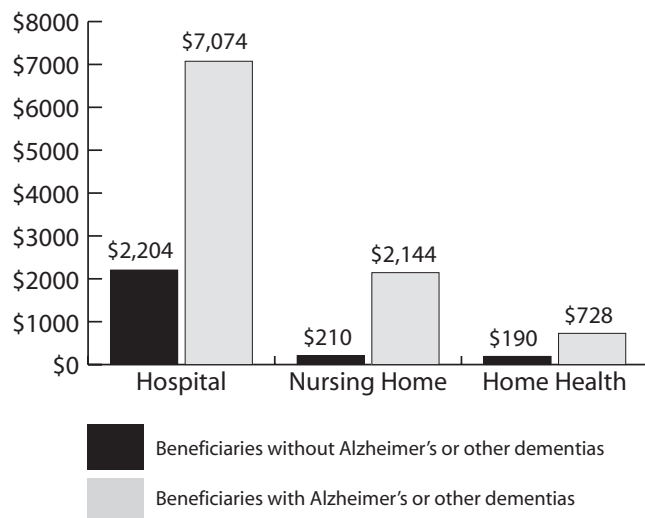
(in billions of dollars)	1998	2002
For workers who are caregivers of people with Alzheimer's	\$26.024	\$36.512
For health care for people with Alzheimer's	\$ 7.144	\$24.634
Total business costs for Alzheimer's disease	\$33.168	\$61.146

Source: Koppel, R. *Alzheimer's Disease: The Costs to U.S. Businesses in 2002*. (For further details, see the Sources in the Appendix.)

FIGURE 2

Average Medicare Costs for Hospital, Nursing Home and Home Health Care for Beneficiaries Age 65+ with Alzheimer's Disease and Other Dementias Compared with Other Beneficiaries, 2000

Source: Alzheimer's Association. *Alzheimer's Disease and Chronic Health Conditions: The Real Challenge for 21st Century Medicare*, 2003. (For further details, see Sources in the Appendix.)



Use of Services

Seventy percent of people with Alzheimer's and other dementias live at home, where they are cared for by family and friends. Even when care is provided in the home, most families must also seek other sources of help, particularly as the disease progresses. People with Alzheimer's disease and other dementias are high users of health care, residential care and home and community services.

Care Settings

The estimated 13 percent of people age 65 and older in the United States with Alzheimer's include 25 percent or more of all elderly users of hospital, nursing home, assisted living, home care and adult day services. Many of these elders have never received a formal diagnosis of the disease.

- About 25 percent of all elderly hospital patients have Alzheimer's disease or other dementias.
- As shown in Table 7, an estimated 70 percent of all nursing home residents have some degree of cognitive impairment. About 47 percent of nursing home residents have a diagnosis of Alzheimer's or another dementia in their medical record.
- Nursing home Alzheimer's Special Care Units had about 91,000 beds in December 2006. Although the number of these units has grown since the 1980s, less than 13 percent of all residents with dementia had access to them in 2006.
- Half or more of all elderly residents of assisted living facilities have Alzheimer's disease or another dementia.
- Twenty-four percent of people of all ages who received Medicare- or Medicaid-funded home health care have moderate to severe cognitive impairment.
- At least half of the elderly participants in adult day services have Alzheimer's disease or another dementia.

Long-term Care

The likelihood of needing long-term care services increases if an older person who cannot perform such daily activities as dressing, bathing, shopping and managing money also has cognitive impairment. One 2002 study of community-living older adults who could not perform at least one customary daily activity found that:

- More than nine out of ten of those with cognitive impairment received assistance from family, friends or paid workers, compared with slightly less than half of those who had no cognitive impairment.

- Nearly one-third of those with cognitive impairment who received any assistance used paid services, usually in combination with unpaid assistance; in contrast, only 12 percent of those who had no cognitive impairment used paid services.
- Those with cognitive impairment who used paid services used almost twice as many hours monthly of that assistance, on average, as those without cognitive impairment (200 hours compared to 108 hours for those without cognitive impairment).
- About 26 percent of these older community-living adults with severe disabilities (defined as those unable to perform three or more daily activities) were also cognitively impaired.

End-of-life Care

Hospice can provide palliative or comfort care that can be helpful for people with Alzheimer's disease and other dementias who are terminally ill. Medicare will cover hospice care if a physician certifies that a beneficiary is likely to die within six months. In general, the Medicare hospice benefit, and hospice care in general, is underutilized. A 2005 study estimated that only 43 percent of patients eligible for hospice ever receive services.

- A recent study investigated hospice referral in people age 65 and older with advanced dementia who died within one year of admission to either a nursing home in Michigan or the state's publicly funded home care and community-based services. The results showed that only 5.7 percent of nursing home residents and 10.7 percent home care clients dying with advanced dementia were referred to hospice.
- One study reported that when persons with Alzheimer's were hospitalized for pneumonia or hip fracture, half died within six months compared to cognitively intact patients, who were less likely to die after receiving the same treatments.
- The study also indicated that hospital patients with Alzheimer's disease often had untreated or undertreated pain.
- The number of hospice admissions for persons with dementia increased from 6.8 percent of all hospice admissions in 2001 to 9.8 percent of all hospice admissions in 2005.

TABLE 7

**Cognitive
Impairment in
Nursing Home
Residents by
State, 2005**

*These figures include
all individuals who spent
any time in a nursing
home in 2005.*

Source:

U.S. Department of
Health and Human
Services, Centers for
Medicare and Medicaid
Services. *Nursing Home
Data Compendium 2005
Edition*. (For further
details, see Sources in
the Appendix.)

		None	Very Mild/Mild	Moderate/Severe
Alabama	48,315	25 percent	26 percent	49 percent
Alaska	1,264	26	29	46
Arizona	39,734	43	24	33
Arkansas	32,641	24	27	49
California	253,565	33	25	42
Colorado	37,363	26	30	44
Connecticut	62,007	35	26	38
Delaware	8,784	37	23	40
District of Columbia	5,892	42	23	35
Florida	201,779	39	23	38
Georgia	64,281	16	25	59
Hawaii	8,127	26	22	52
Idaho	12,476	31	26	43
Illinois	166,043	30	31	39
Indiana	83,962	33	24	43
Iowa	49,394	23	29	48
Kansas	35,606	20	31	49
Kentucky	48,485	29	24	47
Louisiana	45,366	23	27	50
Maine	18,104	34	24	42
Maryland	64,287	37	24	39
Massachusetts	101,704	33	24	43
Michigan	94,499	29	26	45
Minnesota	71,073	28	29	42
Mississippi	27,185	22	27	51
Missouri	75,103	29	29	42
Montana	11,807	29	28	43
Nebraska	26,132	23	30	47
Nevada	11,232	35	24	41
New Hampshire	14,763	28	26	46
New Jersey	112,660	42	24	34
New Mexico	13,711	30	28	43
New York	223,781	33	25	41
North Carolina	83,920	29	25	46
North Dakota	10,755	24	28	48
Ohio	184,049	27	27	46
Oklahoma	37,968	27	30	43
Oregon	26,497	35	27	39
Pennsylvania	177,566	31	26	43
Rhode Island	16,921	28	29	43
South Carolina	35,478	26	22	52
South Dakota	11,532	21	29	50
Tennessee	70,893	25	25	50
Texas	176,041	25	31	44
Utah	16,879	35	29	36
Vermont	6,789	25	29	47
Virginia	66,649	27	28	45
Washington	57,245	30	28	42
West Virginia	21,465	35	21	44
Wisconsin	73,071	33	27	40
Wyoming	5,094	22	29	49
U.S. Total	3,149,937	30	26	44

Special Report: Caregiving

Caregivers of People with Alzheimer's Disease and Other Dementias

Almost 10 million Americans are caring for a person with Alzheimer's disease or another dementia. This figure constitutes about 29 percent of all caregivers of people aged 60 and older.⁴ These caregivers are often providing help for a person who has not only Alzheimer's disease or another dementia, but also one or more other serious medical conditions, such as heart disease or stroke.

These unpaid caregivers provided the nation with an economic asset worth almost \$83 billion in 2005, based on their hours of care.⁵ This figure is not reflected in any formal estimates of national health care costs. (Table 8 provides a state-by-state listing of the number of Alzheimer and dementia caregivers, the hours of care they provide and the economic value of that care.)

The Challenges of Caregiving

Caring for a person with Alzheimer's disease poses special challenges. Although memory loss is the most widely known symptom, as the disease progresses it also causes confusion, loss of orientation and, frequently, changes in personality and behavior. Individuals require increasing levels of care, supervision and provision for their safety. Because the disease gets worse slowly, caregivers tend to spend a long time in the caregiving role. A 2003 National Alliance for Caregiving/AARP survey found that:

- Nearly one in four of the caregivers of people with Alzheimer's disease and other dementias provide 40 hours a week or more of care. Seventy-one percent sustain this commitment for more than a year, and 32 percent do so for five years or more.
- Sixty-five percent of Alzheimer caregivers perform physically demanding kinds of personal care – for example, bathing, feeding, helping the person to the toilet and dealing with loss of bladder or bowel control. These tasks are made more difficult by the confused and disoriented state of the person with dementia, who may be unable to help with the tasks or may resist assistance from the caregiver.
- Caregivers of people with Alzheimer's disease and other dementias are much more likely than other caregivers to help with loss of bladder or bowel control (32 percent of Alzheimer/dementia caregivers, compared with 13 percent of other caregivers) and bathing (35 percent v. 25 percent).

Table 9 compares the percentage of caregivers of individuals with dementia who assist with specific daily activities with the percentage of caregivers assisting with those activities for people without dementia.

Stress Associated with Caregiving

These challenges often affect the health and income of caregivers of people with Alzheimer's and other dementias. Over 40 percent of these caregivers report high levels of emotional stress. Many of them are working full- or part-time, but their work responsibilities can be seriously affected by the demands of caregiving.

- Almost one-quarter of caregivers of people with Alzheimer's and other dementias report that caring for their family member is very stressful, compared to 15 percent of other caregivers who reported that high a level of stress.
- Two-thirds of working caregivers of people with Alzheimer's and other dementias report that they missed work because of caregiving responsibilities, compared with 57 percent of other caregivers.
- Eight percent of working caregivers of people with Alzheimer's and other dementia turned down a promotion (4 percent of other caregivers), and 7 percent lost job benefits (3 percent for other caregivers).
- Almost a third of caregivers of people with Alzheimer's and other dementias got less exercise than they did before they began their caregiving, compared with about a quarter of other caregivers.

A recent study found that among elderly people, hospitalization of a spouse for dementia was associated with an increased risk of death for the non-hospitalized partner. Among men, 8.6 percent died within a year after a spouse's hospitalization for dementia compared to 6.4 percent that died after a spouse's hospitalization for colon cancer and 6.9 percent after a spouse's hospitalization for stroke. Among women, the rate was 5 percent in the year after a spouse's hospitalization for dementia compared to 3 percent that died after a spouse's hospitalization for colon cancer and 3.7 percent after a spouse's hospitalization for stroke.

⁴ See Methodology section in the report's Appendix for a detailed explanation of these figures.

⁵ Economic value is derived by multiplying the estimated number of Alzheimer's and dementia caregivers by the average number of hours of care per year provided by these caregivers and an average hourly wage for paid workers. For further information, see the Methodology section in the report's Appendix.

Another study assessed the type and intensity of care provided by family caregivers of persons with dementia during the year before the care recipient's death. End-of-life care for people with dementia was "extremely demanding of family caregivers," the study found, particularly during a "protracted and stressful" period preceding death. The stress was so great, many of the caregivers said, that they experienced relief when death finally occurred.

The Economic Value of Caregiving

Caregivers of people with Alzheimer's disease and other dementias make significant personal investments of time and energy in caring for their loved ones. Their unpaid care also contributes billions in value to the nation. A total of approximately 9.8 million caregivers of people with Alzheimer's and other dementias nationwide provided care worth almost \$83 billion in 2005. A million of these caregivers in California, for example, provided an estimated \$8.5 billion of care that year. Even Rhode Island, the smallest state, had almost 37,000 caregivers of people with Alzheimer's and other dementias, and those caregivers provided 32 million hours of care worth \$310.7 million. Table 8 provides state-by-state data on the number of caregivers of people with Alzheimer's and other dementias, the hours of care they provide, and the economic value of their caregiving. (See Methodology section in the Appendix for details.)

TABLE 8

**Number of Alzheimer
and Dementia Caregivers,
Hours of Unpaid Care
and Economic Value of
the Care by State, 2005**

	Caregivers	Hours of Unpaid Care per Year	Total Value of Unpaid Care
Alabama	177,175	152,937,066	\$1,495,724,501
Alaska	13,304	11,484,254	\$112,316,005
Arizona	151,810	131,042,195	\$1,281,592,670
Arkansas	114,157	98,540,320	\$963,724,330
California	1,010,596	872,346,303	\$8,531,546,840
Colorado	123,727	106,801,491	\$1,044,518,586
Connecticut	113,015	97,554,542	\$954,083,419
Delaware	29,455	25,425,618	\$248,662,541
District of Columbia	16,034	13,840,716	\$135,362,202
Florida	549,163	474,037,087	\$4,636,082,713
Georgia	311,392	268,793,576	\$2,628,801,169
Hawaii	38,420	33,163,896	\$324,342,901
Idaho	46,563	40,193,561	\$393,093,030
Illinois	357,853	308,898,371	\$3,021,026,070
Indiana	208,817	180,250,419	\$1,762,849,095
Iowa	93,556	80,757,917	\$789,812,426
Kansas	84,306	72,773,022	\$711,720,151
Kentucky	160,908	138,895,482	\$1,358,397,815
Louisiana	168,662	145,588,838	\$1,423,858,831
Maine	48,791	42,116,389	\$411,898,282
Maryland	169,698	146,483,515	\$1,432,608,772
Massachusetts	208,595	180,059,110	\$1,760,978,096
Michigan	364,631	314,749,741	\$3,078,252,463
Minnesota	186,614	161,084,831	\$1,575,409,648
Mississippi	138,750	119,769,006	\$1,171,340,879
Missouri	166,809	143,989,519	\$1,408,217,498
Montana	33,826	29,198,750	\$285,563,773
Nebraska	57,819	49,909,111	\$488,111,105
Nevada	71,045	61,326,396	\$599,772,151
New Hampshire	42,177	36,407,179	\$356,062,207
New Jersey	284,339	245,441,241	\$2,400,415,337
New Mexico	61,343	52,951,053	\$517,861,298
New York	618,994	534,315,379	\$5,225,604,409
North Carolina	311,377	268,780,454	\$2,628,672,839
North Dakota	16,646	14,368,883	\$140,527,674
Ohio	380,106	328,107,835	\$3,208,894,631
Oklahoma	112,451	97,067,799	\$949,323,070
Oregon	120,405	103,933,218	\$1,016,466,869
Pennsylvania	433,909	374,550,216	\$3,663,101,110
Rhode Island	36,807	31,771,953	\$310,729,700
South Carolina	161,390	139,311,602	\$1,362,467,471
South Dakota	25,812	22,280,767	\$217,905,902
Tennessee	232,414	200,620,095	\$1,962,064,526
Texas	690,058	595,658,286	\$5,825,538,039
Utah	75,894	65,511,843	\$640,705,821
Vermont	17,981	15,521,130	\$151,796,652
Virginia	249,726	215,563,228	\$2,108,208,374
Washington	177,369	153,104,826	\$1,497,365,194
West Virginia	79,483	68,609,403	\$670,999,965
Wisconsin	175,329	151,344,154	\$1,480,145,830
Wyoming	15,302	13,208,347	\$129,177,635
Puerto Rico	285,404	246,360,983	\$2,409,410,417
Total	9,820,205	8,476,800,913	\$82,903,112,933

TABLE 9**Helping with Specific Daily Activities, Alzheimer Caregivers Compared with Other Caregivers**

Daily Activities	% Alzheimer/Dementia Caregivers	% Other Caregivers
Getting in and out of bed	46	38
Getting dressed	44	28
Helping bathe or shower	35	25
Getting to and from toilet	33	23
Dealing with incontinence	32	13

Source: Alzheimer's Association and National Alliance for Caregiving. *Families Care: Alzheimer's Caregiving in the United States*, 2004.
(For further details, see Sources in the Appendix.)

Appendix

Methodology

Prevalence

The national and state prevalence figures in this report are based primarily on published studies conducted by a team of researchers from the Rush Institute on Healthy Aging and the Rush Alzheimer's Disease Center in Chicago and the U.S. Centers for Disease Control and Prevention in Atlanta. The research team analyzed the incidence of Alzheimer's disease among residents age 65 and over in a biracial Chicago community, consisting of three adjacent neighborhoods (Hebert et al., 2003). The residents were studied over a four-year period. Seventy-nine percent of all community residents age 65 and over participated in a baseline in-home interview. Data collection consisted of the in-home interview for all participants and a diagnostic evaluation for a stratified random sample of the participants.

Incidence of Alzheimer's disease was measured in 3,838 persons free of Alzheimer's at baseline, and 835 persons had a diagnostic evaluation for Alzheimer's. The incidence figures were converted to prevalence estimates, adjusted for education and other factors, and applied to U.S. Census Bureau population figures for the year 2000 and U.S. Census Bureau projections for the years 2010, 2020, 2030, 2040 and 2050 (Hebert et al. 2003).

In early 2007, at the request of the Alzheimer's Association, the researchers calculated the national prevalence of Alzheimer's disease in people age 65 and over for that year, using linear extrapolation from their previous published estimates for 2000 and 2010.

The researchers calculated the prevalence of Alzheimer's disease in each state by combining the incidence figures from the Chicago study with U. S. Census Bureau figures for the population of the state in 2000, U.S. Census Bureau projections for the state for 2010, and state-specific adjustments for gender, race, education, and mortality (Hebert et al., 2004).

Additional incidence figures used in this report come from a published study of the incidence of Alzheimer's disease in stratified random samples of residents age 65 and over in east Boston (Hebert et al., 2001). Prevalence figures for people under age 65 come from a 2006 Alzheimer's Association report (Alzheimer's Association, 2006) and are based on an analysis of available data from the Health and Retirement Study and other published articles discussed in detail in the report.

Some estimates of the prevalence of Alzheimer's disease and other dementias are lower than the figures used in this report. Differences in prevalence estimates reflect many factors, including age distribution in the sample population (e.g., the proportion of people age 65–74, 75–84 and 85+) and the threshold level of severity required for a diagnosis of Alzheimer's disease. All available estimates indicate that a large number of Americans have Alzheimer's disease and that the number will grow rapidly as our population ages.

Caregiving

In 2000, the Behavioral Risk Factor Surveillance System (BRFSS) included a question about caregiving in the telephone survey conducted by state health departments to track health risks and health behaviors in the country. The survey asked respondents age 18+ whether they had provided any regular care or assistance during the past month to a family member or friend age 60 or over who had a long-term illness or disability; 15.6 percent of the respondents answered this question affirmatively (McKune et al., 2006). When the 15.6 percent figure is applied to the 2005 census figure for the number of people in the U.S. age 18+, the result indicates that in 2005, there were 34 million caregivers for the population specified in the survey question.

In 2003, the National Alliance for Caregiving (NAC) and AARP conducted a national telephone survey to identify people age 18+ who were providing unpaid care for a relative or friend age 18+ or had provided such care during the past 12 months; 21 percent of the respondents reported that they were providing or had provided care for the specified population (National Alliance for Caregiving and AARP, 2004). When the 21 percent figure is applied to the 2005 census figure for the number of people in the U.S. age 18+, the result indicates that in 2005, there were 45.2 million caregivers for the specified population.

The 2003 NAC/AARP survey asked the caregivers about the health problems of the person for whom they provided care, and 23 percent of the caregivers said that: (1) Alzheimer's or dementia was the main problem of the person for whom they provided care, or (2) that the person had Alzheimer's or other mental confusion in addition to his or her main problem (for example, heart disease or stroke) (National Alliance for Caregiving and AARP, 2004). When the 23 percent figure is applied to the 45.2 million caregivers, the result indicates that there were 10.4 million caregivers of people age 18+ with Alzheimer's, dementia or other mental confusion.

There is no data to calculate the proportion of caregivers of people age 60+ that is providing care for a person with Alzheimer's or another dementia. To estimate that proportion, the number of caregivers of people with Alzheimer's, dementia or other mental confusion from the 2003 NAC/AARP survey (10.4 million) was divided by the number of caregivers of people age 50+ from the NAC/AARP survey (35.7 million), assuming that almost all care recipients with Alzheimer's, dementia or other mental confusion in the survey sample would be age 50+. The result indicated that 29 percent of caregivers of people age 50+ provided care for a person with Alzheimer's, dementia or other mental confusion. The 29 percent figure was used as a conservative estimate of the proportion of caregivers of people age 60+ who provided care for a person with Alzheimer's or another dementia. When the 29 percent figure is applied to the BRFSS-based figure of 34 million caregivers of people age 60+ in 2005, the result indicates that there were 9.8 million caregivers of a person age 60+ with either Alzheimer's or dementia as his or her main condition or Alzheimer's or other mental confusion in addition to his or her main condition.

A follow-up analysis of data from the 2003 NAC/AARP survey focused on caregivers of people with Alzheimer's disease and other dementias (Alzheimer's Association and the National Alliance for Caregiving, 2004). This study found that these caregivers provided an average of 16.6 hours of care per week.⁶ The number of caregiving hours per year in 2005 (8.5 billion hours) was derived by multiplying an average of 16.6 hours per week by the number of Alzheimer caregivers (9.8 million) by 52 weeks in a year.

The cost per hour of care is based on the method of Arno et al. (1999). This method uses the average of a low and high estimate of the dollar value of an hour of unpaid family care. The low estimate is the minimum wage, \$5.15 in 2005; the high estimate comes from the Bureau of Labor Statistics and varies by month. The figure for July 2005, \$14.41, was used. The average of those two figures is \$9.78.

When the 8.5 billion hours of Alzheimer and dementia care is multiplied by \$9.78 an hour, the result is \$82.9 billion.

Figures were reviewed from other analyses of number of caregivers, hours of care provided and economic value of the

care. These analyses differ in many ways, including the source of the data, the definition of caregiver, the required period of caregiving (i.e., current only or current and past caregiving), the attributed replacement cost for an hour of unpaid care and the year for which estimates are provided. For example:

- Langa et al. (2001) calculated number of caregivers, hours of informal care and net value of caregiving for people age 70+ with dementia for the year 1998; the study identified only 2 million caregivers, excluding several categories of caregivers that are included in the above analysis (e.g., caregivers of people with dementia in nursing homes, caregivers of people under age 70 with dementia, and caregivers who provided assistance only some of the time or occasionally). The study found that caregivers provided an average of 25.4 hours of care per week, a figure much higher than the 16.6 hours used for this analysis.
- Arno (2006) calculated number of caregivers, hours of informal care, and total value of caregiving for people age 18+ with any disease or condition for the year 2004. He estimated that there were 28.8 million caregivers in the U.S., and that they provided an average of 20.6 hours of care per week, again a figure much higher than the 16.6 hours used for this analysis.

Because of differences among these analyses, direct comparisons are not possible. It is clear, however, that most other analyses include a smaller number of caregivers and a higher average number of hours per week of care. The NAC/AARP analysis included many caregivers who provided relatively few hours per week of care. As noted, 47 percent of them provided an average of only four hours per week of care⁶. Such caregivers include secondary caregivers, who may provide respite or specific help to assist the primary caregiver, caregivers of people in the early stages of Alzheimer's or another dementia who do not yet need a lot of assistance, and caregivers of nursing home residents with Alzheimer's or other dementias who receive most of their hands-on care from the facility staff. Inclusion of these caregivers in our analysis increases the total number of caregivers and decreases the average hours of care provided in comparison with other analyses.

⁶ The NAC/AARP average is based on data showing that 23 percent of these caregivers provided 40 or more hours of care a week; 8 percent provided an average of 30 hours per week; 21 percent provided an average of 15 hours a week; 47 percent provided an average of four hours a week; and 1 percent did not report their hours of care.

Sources

Prevalence

Alzheimer's Association. *Early Onset Dementia: A National Challenge, A Future Crisis*. (Washington, D.C.: Alzheimer's Association, June 2006), accessible at www.alz.org; search "early onset report."

Boustani, M; Callahan, CM; Unverzagt, FW; Austrom, MG; Perkins, AJ; Fultz, BA; Hui, SL; and Hendrie, HC. "Implementing a Screening and Diagnosis Program for Dementia in Primary Care." *Journal of General Internal Medicine* 2005; 20:572-577.

Hebert, LE; Beckett, LA; Scherr, PA; and Evans, DA. "Annual Incidence of Alzheimer Disease in the United States Projected to the Years 2000 through 2050." *Alzheimer Disease and Associated Disorders* 2001; 15:169-173.

Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; and Evans, DA. "Alzheimer Disease in the U.S. Population: Prevalence Estimates Using the 2000 Census." *Archives of Neurology* 2003; 60:1119-1122.

Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; and Evans DA. "State-specific Projections through 2025 of Alzheimer Disease Prevalence." *Neurology* 2004; 62:1645, and additional online material related to this article at www.neurology.com.

Mortality

Alzheimer's Association. *Alzheimer's Disease and Chronic Health Conditions: The Real Challenge for 21st Century Medicare* (Washington, D.C.: Alzheimer's Association, 2003), accessible at www.alz.org; search "Alzheimer's disease and chronic health conditions."

American Cancer Society, Statistics, *Cancer Facts and Figures – 2000* and *Cancer Facts and Figures – 2004*, accessible at http://www.cancer.org/docroot/stt/stt_0.asp.

Bynum, JPW; Rabins, PV; Weller, W; Niefeld, M; Anderson, GF; and Wu, AW. "The Relationship Between a Dementia Diagnosis, Chronic Illness, Medicare Expenditures and Hospital Use." *Journal of the American Geriatrics Society* 2004; 52:187-194.

Ebell, MH; Becker, LA; Barry, HC; and Hagen, M. "Survival After In-hospital Cardiopulmonary Resuscitation. A Meta-analysis." *Journal of General Internal Medicine*. 1998; 13:805-816.

Ganguli, M; and Rodriguez, EG. "Reporting of Dementia on Death Certificates. A Community Study." *Journal of the American Geriatrics Society* 1999; 47:842-849.

Hill, JM. "Hospice Utilization: Political, Cultural, and Legal Issues." *Journal of Nursing Law* 2005 Winter; 10(4): 216-224.

Hoyert, DL. *Mortality Trends for Alzheimer's Disease, 1979-91*. National Center for Health Statistics. *Vital and Health Statistics* 1996; 20 (28), accessible at www.cdc.gov/nchs; search for "mortality trends for Alzheimer's disease, 1979-91."

Larson, EB; Shadlen, M; Wang, L; McCormick, WC; Bowen JD, Teri L; and Kukull WA. "Survival After Initial Diagnosis of Alzheimer's Disease." *Annals of Internal Medicine* 2004; 140:501-509.

Maslow, K. "Dementia and Serious Coexisting Medical Conditions: A Double Whammy." *Nursing Clinics of North America* 2004; 39:561-579.

Mitchell, SL; Kiely, DK; and Hamel, MB. "Dying With Advanced Dementia in the Nursing Home." *Archives of Internal Medicine* 2004; 164:321-326.

Mitchell, SL; Morris, JN; Park, PS; and Fries, BE. "Terminal Care for Persons With Advanced Dementia in the Nursing Home and Home Care Settings." *Journal of Palliative Medicine*, 2004 Dec; 7(6):808-816.

U.S. Centers for Disease Control and Prevention, National Center for Health Statistics, *Mortality Data From the National Vital Statistics System*, accessible at www.cdc.gov/nchs/deaths.htm.

Volicer L. End-of-life Care for People With Dementia in Residential Care Settings (Alzheimer's Association, 2005) accessible at www.alz.org/national/documents/endoflifelitreview.pdf.

Medicare and Medicaid

Alzheimer's Association. *Alzheimer's Disease and Chronic Health Conditions: The Real Challenge for 21st Century Medicare* (Washington, D.C.: Alzheimer's Association, 2003), accessible at www.alz.org; search "Alzheimer's disease and chronic health conditions."

Federal Interagency Forum on Aging Related Statistics. *Older Americans 2004: Key Indicators of Well-being*, accessible at <http://agingstats.gov/chartbook2004/default.htm>.

Kaiser Commission on Medicaid and the Uninsured. *The Distribution of Assets in the Elderly Population Living in the Community*. (Washington, D.C.: Henry A Kaiser Family Foundation, 2005), accessible at <http://www.kff.org>.

MetLife Mature Market Institute. *The MetLife Market Survey of Nursing Home and Home Care Costs*. September 2006, accessible at www.metlifemarketinstitute.com; click on "studies" and on "2006 Metlife Market Survey of Nursing Home and Home Care Costs."

Urban Institute, unpublished tabulations for the Alzheimer's Association from the 2000 Medicare Current Beneficiary Survey and Medicare Claims, 2005.

U.S. Administration on Aging. *A Profile of Older Americans: 2005*, accessible at <http://www.aoa.gov/PROF/Statistics/profile/2005/profiles2005.asp>

U.S. Census Bureau. Income, Poverty, and Health Insurance Coverage in the United States: 2004. U.S. Department of Commerce, Aug. 2005, accessible at www.census.gov/prod/2005pubs/p60-229.pdf.

U.S. Department of Health and Human Services. *Health Care Financing Review: Medicare and Medicaid Statistical Supplement, 2003*. February, 2005.

Costs to the Nation

Alzheimer's Association. *Alzheimer's Disease and Chronic Health Conditions: The Real Challenge for 21st Century Medicare* (Washington, D.C.: Alzheimer's Association, 2003), accessible at www.alz.org; search "Alzheimer's disease and chronic health conditions."

Caplan, C; and Brangan, N. *Out-of-Pocket Spending on Health Care by Medicare Beneficiaries Age 65 and Older in 2003*. AARP Public Policy Institute. DD#101. September 2004, accessible at www.aarp.org/research/medicare/outofpocket/aresearch-import-912-DD101.html.

Koppel, R. *Alzheimer's Disease: The Costs to U.S. Businesses in 2002* (Washington, D.C.: Alzheimer's Association, June 2002), accessible at www.alz.org; search "Alzheimer's Disease: The Costs to U.S. Businesses in 2002."

Langa, KM; Larson, EB; Wallace, RB; Fendrick, AM; Foster, NL; Kabeto, MU; Weir, DR; Willis, RJ; and Herzog, AR. "Out-of-pocket Health Care Expenditures Among Older Americans With Dementia." *Alzheimer Disease and Associated Disorders*. 2004;18:90-98.

Lewin Group. *Saving Lives. Saving Money: Dividends for Americans From Investing in Alzheimer Research* (Washington, D.C.: Alzheimer's Association, 2004), accessible at www.alz.org; search "Saving Lives, Saving Money."

Machlin, SR; and Zodet, MW. *Out-of-pocket Health Care Expenses by Age and Insurance Coverage, 2003*. Agency for Healthcare Research and Quality. Medical Expenditure Panel Survey. Statistical Brief #126. May 2006.

MetLife Mature Market Institute. *The MetLife Market Survey of Assisted Living Costs*. October 2006, accessible at www.metlifemarketinstitute.com; click on "studies" and on "2006 Metlife Market Survey of Assisted Living Costs."

MetLife Mature Market Institute. *The MetLife Market Survey of Nursing Home and Home Care Costs*. September 2006, accessible at www.metlifemarketinstitute.com; click on "studies" and on "2006 Metlife Market Survey of Nursing Home and Home Care Costs."

Partners in Caregiving. *A National Study of Adult Day Services 2001-2002* (Winston-Salem, N.C.: Wake Forest University School of Medicine, 2002).

U. S. Centers on Medicare and Medicaid Services. *Medicare Current Beneficiary Survey, 2002 Cost and Use Public Use File*. Table 4.1: Personal Health Care Expenditures for Medicare Beneficiaries, by Source of Payment and Type of Medical Service, 2002.

Use of Services

Alzheimer's Association. *Medicare's Hospice Benefit for Alzheimer Beneficiaries: Frequently Asked Questions*, 2006, accessible at www.alz.org/national/documents/FSHospiceBenefit.pdf.

Johnson, RW; and Wiener, JM. *A Profile of Frail Older Americans and their Caregivers*. (Washington, D.C.: Urban Institute, Feb. 2006), accessible at www.urban.org/publications/311284.html.

Maslow, K. "How Many Hospital Patients Have Dementia," N. Silverstein and K. Maslow (eds.) *Improving Hospital Care for People With Dementia* (New York, NY: Springer Publishing Co., 2006).

Morrison, RS; and Siu, AL. "Survival in End-stage Dementia Following Acute Illness." *Journal of the American Medical Association* 2000; 284:47-52.

National Hospice and Palliative Care Organization. *NHPCO's Facts and Figures, 2005 Findings, and 2004 National Summary Statistics and Trends*, accessible at www.nhpco.org.

Partners in Caregiving. A National Study of Adult Day Services 2001-2002 (Winston-Salem, NC: Wake Forest University School of Medicine, 2002).

Rosenblatt, A; Samus, QM; Steele, CD; Baker, AS; Harper, MG; Brandt, J; Rabins, PV; and Lyketsos, CG. "The Maryland Assisted Living Study: Prevalence, Recognition, and Treatment of Dementia and Other Psychiatric Disorders in the Assisted Living Population of Central Maryland." *Journal of the American Geriatrics Society* 2004; 52:1618-1625.

Sloane, PD; Zimmerman, S; and Ory, MG. "Care for Persons With Dementia," in *Assisted Living: Needs, Practices, and Policies in Residential Care for the Elderly*, S Zimmerman, PD Sloane, and JK Eckert (eds) (Baltimore, MD: Johns Hopkins University Press, 2001) pps. 242-270.

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, OSCAR data for June 2006, accessible at http://www.ahca.org/research/oscar/rpt_MC_mental_status_200606.pdf and http://www.ahca.org/research/oscar/rpt_special_care_beds_200606.pdf.

U. S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, *Nursing Home Data Compendium 2005 Edition*, pps. 53, 77-82; accessible at <http://www.cms.hhs.gov/apps/files/NHDataComp2005.zip>.

U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Unpublished data from Rollup Summary Reports, Case Mix Means and Episode Counts, National Values for the 12-month period from Mar 2003-Feb. 2004, Baltimore, Md.

Caregiving

Alzheimer's Association and National Alliance for Caregiving. *Families Care: Alzheimer's Caregiving in the United States*, 2004 (Washington, D.C.: 2004), accessible at www.alz.org; search "families care."

Arno, PS. *Estimated Prevalence and Economic Value of Family Caregiving, by State (2004)*, accessible at www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1805.

Arno, PS; Levine, C; and Memmott, MM. "The Economic Value of Informal Caregiving." *Health Affairs*. 1999; 18:182-188.

Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Behavioral Risk Factor Surveillance System, accessible at <http://www.cdc.gov/brfss>.

Christakis, NA; and Allison, PD. "Mortality After the Hospitalization of a Spouse." *New England Journal of Medicine* 2006; 354:719-730.

Langa, KM; Chernew, ME; Kabeto, MU; Herzog, AR; Ofstedal, B; Willis, RJ; Wallace, RB; Mucha, LM; Straus, WL; and Fendrick, AM. "National Estimates of the Quantity and Cost of Informal Caregiving for Elderly With Dementia." *Journal of General Internal Medicine* 2001; 16:770-778.

McKune, SL; Andresen, EM; Zhang, J; Neugaard, B. *Caregiving: A National Profile and Assessment of Caregiver Services and Needs*. University of Florida and Rosalynn Carter Institute, 2006, accessible at www.rosalynncarter.org.

National Alliance for Caregiving and AARP. *Caregiving in the U.S.* (Bethesda, MD: National Alliance for Caregiving and AARP, Feb. 2004), accessible at www.caregiving.org/pubs/data.htm.

Schulz, R; Mendelsohn, AB; Haley, WE; Mahoney, D; Allen, RS; Zhang, S; Thompson, L; and Belle, SH. "End-of-life Care and the Effects of Bereavement on Family Caregivers of Persons With Dementia." *New England Journal of Medicine* 2003; 349:1936-42.

U.S. Census Bureau, American FactFinder, *General Demographic Characteristics: 2005*, American Community Survey, accessed at <http://factfinder.census.gov>.

U.S. Department of Labor, Bureau of Labor Statistics.
"Employment and Earnings: Home Health Care Services (NAIC code 6216) Establishment data: hours and earnings, home health care services."

Notes

Notes



The Alzheimer's Association, the leading voluntary health organization in Alzheimer research and support, is dedicated to finding prevention methods, treatments and an eventual cure for Alzheimer's.

Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's disease.

Alzheimer's Association
National Office
225 N. Michigan Ave., Fl. 17
Chicago, IL 60601-7633

Alzheimer's Association
Public Policy Office
1319 F Street N.W. Suite 500
Washington, D.C. 20004-1106

1.800.272.3900

www.alz.org